CONCLUSION

This set of related studies was undertaken with the knowledge that most service providers believe respite programs are both desired by, and useful for, families caring for persons afflicted with Alzheimer's disease. The focus has been on the manner in which a diverse population of caregiving families used respite services, the beliefs of these families about caregiving and their preferences for services. The intent was not to determine the outcomes of respite program for clients, but to profile the patterns of respite use that occur when services are made available in a culturally appropriate manner and at a reasonable cost to families in their own communities.

This report includes a large number of findings regarding behaviors and preferences of family members who provide care for their relatives have been reported. To capture more fully the utility of these findings for policy, the results of this work are summarized and discussed here under four major themes. In the final section, six implications for practice are delineated to facilitate the translation of this research into practice.

1. CULTURE AND DIVERSITY OF CAREGIVING CONTEXTS

There is great diversity among caregivers in the contexts within which they provide care and their beliefs about family and government obligations. These differences are primarily associated with ethnicity and the relationship of the caregiver to the care recipient.

Findings from this study add to a large body of literature that has documented the diversity of caregivers. With the exception of ethnicity and geographic location, the demographic characteristics of caregivers included in the ADDGS studies were similar to those of caregivers included in most other studies of caregiving and respite use. Almost three-quarters of the caregivers were female. Approximately 37% were spouses and 46% were adult children (see Conclusion Appendix for full description). Just over 10% of the caregivers were more distant relatives. Consistent with the goal of the ADDGS demonstration to serve minority and rural populations, a much larger proportion of the caregivers in the ADDGS than in other samples of caregivers were Black/African-American (32%), Hispanic/Latino (8%) and just over 53% resided in rural areas.

Generational Differences

A number of characteristics that distinguish spouse caregivers from those who are adult children or other relatives are important in terms of differences in expectations, service needs and delivery systems. First, almost all spouses lived with the care recipient and they resided in a household that included only the caregiving dyad. In contrast only 63% of adult children and 35% of other relatives in this study resided with the care recipient. Second, only a few spouses were employed outside of the home, while 52% of adult children were employed outside of the home.   Third, past research has noted that spouses tend to spend a greater number of hours providing care and the care that they provide tends to be more intense including more personal care (Montgomery & Kosloski, 2000). This pattern was also observed for the caregivers in the ADDGS study by many of the providers who participated in the interviews. Fourth, spouses reported a higher level of affection for the care recipient and a greater sense of obligation to provide care than did adult children or other caregivers. Finally, at the time that spouse caregivers entered the demonstration program seeking services, they had been providing care for a longer period of time and were caring for elders who were more significantly impaired. The mean length of caregiving for spouse caregivers in the longitudinal sample was 45 months, while the mean length of caregiving for adult children was 39 months. The mean ADL score at intake was 4.4 for elders assisted by spouses in contrast to 3.8 for elders assisted by adult children. Similarly, elders cared for by spouses had a mean score of 13.4 on the measure of problem behaviors as opposed to 13.1 for elders with an adult child caregiver.

Gender Differences

Although this project did not assess gender differences in caregiving behaviors, past research has noted gender differences with respect to caregiving tasks that may well account for differences in patterns of respite use that were observed in this study. While the majority of previous studies have reported no gender differences in the level of affection for the care recipient or in obligation to provide care, significant differences between males and females have been observed in the amount and type of care provided especially among adult children caregivers. In general, female caregivers provide a greater amount of care and more intense care than do males. In contrast,

males tend to seek and obtain more assistance with their caregiving tasks than do women (see Montgomery & Kosloski, 2000 for a review of this literature).

Ethnicity

Cultural differences were observed in key demographic characteristics of the study samples and in beliefs about the appropriate roles of family and government for providing long term care.   Both types of differences appear to have implications for service delivery. Among Whites, spouses are much more likely to be the primary care provider. In contrast, adult children are more prevalent as caregivers for other ethnic groups especially Black/African-Americans. Consequently, care recipients from these minority groups are more likely to reside in larger households and their caregivers are more likely to have another person available for back-up assistance. This is especially true for Hispanic/Latinos who also report greater satisfaction with the level of social contact they have, and the help that they receive from their informal support network than do either Black/African-Americans or Whites.

In general, the beliefs expressed by both Black/African-American and Hispanic/Latino caregivers about long term care differ significantly from those of Whites. Caregivers from the two minority groups expressed a greater affection and respect for the care recipient and higher levels of religiosity. Also Black/African-Americans reported greater reliance on religion and religious groups for emotional support. At the same time, when directly asked, caregivers from both minority groups expressed greater expectations for help from government sources and less guilt in receiving help from outside sources. This finding is somewhat perplexing given the consistent reports among service providers that minority groups are skeptical users of government services.

2. PATTERNS OF RESPITE USE

Diversity among caregivers created a corresponding diversity in the types of services that caregivers seek and the manner in which they use respite services.

Clear patterns were observed that indicate that caregivers seek and continue to use services that they perceive as useful to their caregiving context. Similarly, caregivers ceased using services that they perceived to be inappropriate or difficult to use. Indeed, almost one third of the clients included in this study were brief users who used services for only one or two months.

Day Care Services

In general, this set of studies support the conclusion that most day care centers have limited capacity to care for persons who exhibit problem behaviors or who have high functioning impairments. Day care is more often used for extended periods when the caregiver is an adult child who must be away from home or who has other family obligations. These caregivers are caring for less impaired elders who engage in fewer problem behaviors. Many of the day care users are seeking a respite program that will allow them to maintain their employment outside of the house. These employed caregivers are most likely to continue to use day care steadily for longer periods of time. However, adult children also need services to be available consistently throughout the week for extend periods of time. Hence, brief use was also more prevalent when programs placed stricter limits on the number of hours of care available to a client.

Consistent with the of greater prevalence of adult children as caregivers among minority groups, both Black/African-American and Hispanic/Latino caregivers are more likely to use day care services than are Whites, and are less likely to be brief users of the services. Finally, the patterns of respite use reflect gender differences in use of formal supports. When the primary caregiver is a son rather than a daughter, the elders use more day care. Similarly when the primary caregiver is a wife rather than a husband, the elder uses less day care.

In-home Services

In-home services tend to be the first choice of spouse caregivers. Caregivers who have been providing care for the longest periods of time for elders who have greater levels of impairment use in-home programs. For many users of in-home services, day care programs are not sufficient to meet their needs. Most often persons using in-home care

for any extended period of time seek programs that offer personal care and professional staffing. It is also noteworthy that like day care, in-home services are used in greater quantities by male caregivers.

The absence of ethnic differences in patterns of in-home use probably reflects the high level of need among those who use in-home respite services. For those persons who use in-home services, the need for care outweighs most other factors, such as program characteristics, which might affect the duration or intensity of use.

Finally, it is important to note that the highest intensity of use is observed among middle-income caregivers ($30,000 to $50,000). Because this pattern is inverse to that observed for nursing home use, it suggests that use of in-home services is influenced by the relative cost to families of in-home care as compared to nursing home care. For families with incomes in the mid range, in-home services may be the least expensive form of long-term care. The cost of nursing home placement can be prohibitive and therefore these middle-income families may use higher quantities of in-home services to help them delay placement of a highly impaired elder. In contrast, families with greater resources can often afford the costs of nursing homes when elders have high levels of care needs. Similarly, families with the lowest incomes are eligible for Medicaid and, thus, can afford nursing home care. At the same time, however, Medicaid does not generally cover in-home services so these families may not have the option of using in-home services. In short, the costs of long term care that must be borne by families appear to be a structural factor that influences service utilization.

3. VALUE OF MULTIPLE FORMS OF RESPITE PROGRAMS

A variety of types of respite services are needed to meet the requests of different service populations. The distinct patterns of service use that were observed for different segments of the caregiving population underscore the importance for communities to offer a respite services in an array of formats. Optimally, a community would offer a full continuum of services.

Caregivers are active agents in choosing support services. The patterns of respite use observed in the longitudinal data suggest that the choices that caregivers make are influenced by both structural factors and by caregivers' perceptions of their own needs.

Many adult children caregivers are dealing with multiple family obligations which often include being the primary breadwinner. These caregivers need a day care program that will fully relieve them of caregiving tasks while they are at work. In-home programs tend to be too expensive to meet the needs of this group and group day programs do not offer the consistency of care that is required.

For some caregivers, respite programs provide an important and useful break from their caregiving activities. If the elder is only mildly impaired, a group day care program offered on a weekly or bi-weekly basis may be quite sufficient. If, however, the elder is more impaired or engages in too many problem behaviors, day care use may be inappropriate. Caregivers assisting these more highly impaired elders may find short, regular in-home visits to be useful.

Among users of in-home services there can also be variation in the care levels that are required. For the most impaired elders, caregivers are concerned that volunteers may not have the level of skills required to care for the elder. Therefore family members providing high levels of care may shy away from programs that use volunteers.

Finally, findings from the analysis indicate that many caregiving situations change over time and caregivers need the opportunity to transition to more appropriate types and levels of care. If the appropriate level or type of care is not available, caregivers often choose to abdicate the caregiving role. This is especially true for adult children who are more likely to have competing demands in their lives.

The variety of needs among caregivers and the diversity of caregiving situations underscore the value of multiple forms of respite in a community. Without multiple types and levels of care, many families will go unserved or under-served. When programs are not available in the right form, caregivers either do not use any services or they use

services for only a brief period. Not all respite is equal and no program can adequately serve the full diversity of caregivers in a community.

4. THE INFLUENCE OF PROVIDER CHARACTERISTICS

Provider characteristics influence the patterns of use or non-use of services as well as client satisfaction with services. When making decisions about service use, families judge the **appropriateness** of a service for their family context and the **accessibility** of the service.

Previous studies of respite care have given little attention to the influence of provider characteristics on patterns of service use. Although the functional level of the elder and the caregiving context largely define the needs of a family for different levels of service, findings from all three studies underscore the impact of provider characteristics on the ability and willingness of families to use services. This series of studies identified three sets of provider characteristics that influence clients' service use, _the amount and level of service, quality of staff, effective communication with family members_.

Appropriate Targeting of Services

As noted above, respite programs must match the level of care provided to a client's level of functioning. Services that are limited in capacity such that they can provide care for only high functioning or only low functioning clients automatically restrict their potential client pool. To successfully serve caregivers, it is important for providers to recognize this limitation.

In addition to the level of care offered, appropriateness of a service can also be determined by the amount of service made available. Programs that offer only a limited number of hours of care are not appropriate for families caring for highly impaired elders or caregivers with employment responsibilities.

Cost counts, but it is not necessary to make all services free. In fact, many providers noted that there was a stigma associated with free services for many families who perceived them as welfare. Sliding scale fees and co-payments can also help providers

make many services available in sufficient quantities. However, when the level of service that is needed requires professional workers who can provide health care services, it is important to identify set fee structures so that families can incorporate these costs into their budgets in a planned manner.

Finally, caregivers are more willing to use day care programs that include activities, music and food that are familiar to the client.

Quality of Staff

Caregivers also make judgments about the quality and appropriateness of staff members, which influences their willingness to use services. There is a clear preference for workers who are knowledgeable about the disease process and community resources, sensitive to the values and cultural background of the family, respectful of the elder, and friendly and easy to talk with.

When well-trained workers who demonstrate sensitivity and respect staff respite programs, families tend to trust them and be more satisfied with the programs. Although the employment of workers who are similar in ethnic background to clients can expedite the creation of trust for the worker, such similarity is not a requirement for a successful program. Caring, skilled staff members of any cultural background can be trained to understand different cultural views and communicate well with families.

Effective Communication

Effective communication that clearly informs caregivers about the nature of program services is an essential component of a respite program that is judged satisfactory by clients and providers. The most consistent finding regarding client satisfaction with services centered on the value of clear communication. Regardless of the cultural background, the relationship of the caregiver to elder, or geographic location, caregivers were most satisfied when they were able to communicate clearly with staff members and when they had clear expectations about the services to be provided and how to obtain them.

Effective communication, however, goes beyond a common language. Although the employment of bilingual staff members can be very important for the Hispanic/Latino populations for whom English is often a second language, good communication entails much more. Family members are most satisfied when workers use non-technical language, listen carefully to families' needs, and demonstrate openness to an exchange of information.

It is also extremely important that families clearly understand the responsibilities and expected behaviors of workers. This is especially true for in-home workers for whom families may have very unrealistic expectations. Satisfaction comes when workers' behaviors match the families' expectations. Therefore it is important to clarify these expectations at the outset. It is also important to make services easily accessible to families by helping them communicate their needs and receive the services of the type and quantity they desire.

Finally, families need to be reassured that respite programs are not a replacement for their own efforts. Programs that work with family members as team members tend to be perceived as more appropriate.

PRACTICE AND POLICY IMPLICATIONS

When the broad array of findings is considered together, several general implications for program design and service delivery can be delineated.

1. The efficient and effective use of program resources dictates careful consideration of patterns of service use for different segments of the target population. These studies identified a range of different long term patterns of service use that are associated with the relationship of the caregiver to the elder and with ethnicity. To plan for future service needs, it is important to consider these trajectories in conjunction with the prevalence of the different segments of the population in the programs' catchment area.

2. When developing a new respite program, it is important to create a service that complements other services available in the community in an effort to make a full continuum available. Not all programs are appropriate for all caregivers. If a community can offer only one form of respite, providers need to learn as much as possible about the prevalence of different types of caregiving contexts in the community to best meet the community's needs.

3. Existing programs may want to carefully consider the characteristics of the clients they are currently serving and note the characteristics of those who are going unserved. All policy decisions regarding availability of services reflect values about who should be served and at what cost. It is not always possible for programs to serve all segments of the caregiving population. However, it is important for policy makers to consciously consider which groups of persons they choose to serve. For example, day care programs that are not offered daily or throughout the normal workday clearly will not serve the majority of employed caregivers. A well-planned program will consider such issues carefully.

4. Once a respite program has been developed, it is important to target the service to the appropriate segments of the caregiving population. Programs that carefully target services and/or alter eligibility rules or the number of hours of service available will be able to reduce the number of families that enroll in services for only brief periods. These families can be costly to programs due to the high costs associated with initial enrollment of clients.

5. The hiring and training of competent, caring workers is a key element in creating a successful respite program. All staff members should be trained to be sensitive to the diversity of caregiving situations and to communicate with families in an open, effective, and clear manner. Existing programs might want to assess the communication skills of their staff members and/or modify the ways in which they communicate information about the services to families. Attention needs to be given to both the content of communications and the way in which information is delivered. Clarity is essential.

6. Careful consideration should be given to policy decisions that place limits on access to respite services. For example, the level at which services are capitated clearly influences service use. Not all families benefit from the same dosage or amount of respite and it is possible for programs to be ineffective because the amount of service offered is insufficient.